SPLAINE CONSULTING

Dementia: A Woman's Global Health Issue

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INTRODUCTION

The burden of dementia is rapidly becoming a challenge to our global economic, health, and social landscape for both men and women. Just recently Dr. Margaret Chan, the Director-General of the World Health Organization made a monumental move to declare dementia as a global health priority in a 2012 WHO report. Dr. Chan stated, "The need for long-term care for people with dementia strains health and social systems, and budgets. The catastrophic cost of care drives millions of households below the poverty line. The overwhelming number of people whose lives are altered by dementia, combined with the staggering economic burden on families and nations, makes dementia a public health priority" (World Health Organization, 2012). Another champion of dementia, David Cameron who leads the advancement of the Millennium Development Goals and is the Prime Minister of the United Kingdom, made his latest pronouncement on dementia. In his speech this past March Cameron declared, "There is that essential spirit of defiance that we in this room share that together we're not going to shrug our shoulders or be defeated by this but instead we're going to work relentlessly to improve lives, to help hundreds of thousands of families to take the fight to dementia" (Cameron, 2012).

Although these proclamations are a tremendous gain in dementia awareness, a global response to dementia is needed but with a gendered approach. Due to the profound effects of the ageing population and changes in demographic and societal trends, women bear the weight of dementia in numerous ways as they are shouldering most of the disease and caregiving burden. In many parts of the world, women are a vulnerable population and are subject to discrimination which is exemplified in their low education and high poverty rates. In addition to declaring dementia as a woman's health priority, chronic disease prevention and ageing issues must be transparent in future MDGs that are critical to determining policy, political agendas, and funding as the current MDGs are set to expire at the end of 2015. But first, it is important to differentiate between the terms 'sex' and 'gender' as sex is a biologically constructed term while gender is socially and culturally constructed. As a woman's health issue, factors related to sex and gender exacerbate the attention women need on this emerging disease. Although Alzheimer's disease is one of the most common forms of dementia, it is often used as an umbrella term for multiple conditions that cause dementia. But for purposes of this report, all forms of irreversible dementia are included.

Global Prevalence and Economic Impact

To understand the effect on women, it is critical to grasp the overall global and economic impact dementia has starting with the ageing population as age is the strongest risk factor for dementia. Worldwide the elderly population is rapidly increasing and by 2050, adults over the age of 60 are expected to reach two billion as displayed in the figure below (World Health Organization, 2012). By 2020, the oldest segment of the population will increase by 200% in low- and middle-income countries and 68% in developed countries (Alzheimer's Disease International, 2009) which is problematic because it is widely accepted that the main risk factor for dementia is age. In fact, the prevalence of dementia is projected to double every five years after the age of 65 (Bamford, 2011). As of 2010, dementia affected 35.6 million people worldwide and is expected to grow rapidly to 65.7 million in 2030 and 115.4 million in 2050 with low- and middle-income countries increasing at faster rates. Almost three-quarters of dementia cases will reside here with most of Asia and Africa experiencing the fastest growth rate shown in the table to the right (Alzheimer's Disease

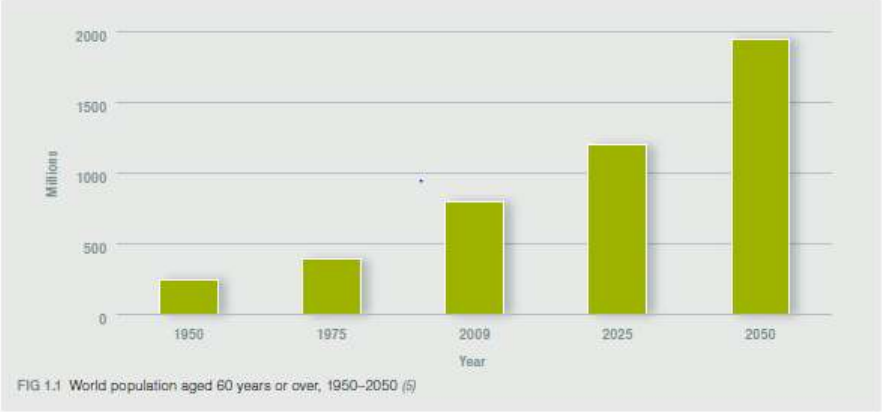


FIG 1.1 World population aged 60 years or over, 1950–2050 (5)

Table 1 Total population over 60, crude estimated prevalence of dementia (2010), estimated number of people with dementia (2010, 2030 and 2050) and proportionate increases (2010-2030 and 2010-2050) by GBD world region

GBD Region	Over 60 population (millions)	Crude estimated prevalence (%)	Number of people with dementia (millions)			Proportionate increases (%)	
	2010	2010	2010	2030	2050	2010-2030	2010-2050
ASIA	**406.55**	**3.9**	**15.94**	**33.04**	**60.92**	**107**	**282**
Australasia	4.82	6.4	0.31	0.53	0.79	71	157
Asia Pacific High Income	46.63	6.1	2.83	5.36	7.03	89	148
Oceania	0.49	4.0	0.02	0.04	0.10	100	400
Asia, Central	7.16	4.6	0.33	0.56	1.19	70	261
Asia, East	171.61	3.2	5.49	11.93	22.54	117	311
Asia, South	124.61	3.6	4.48	9.31	18.12	108	304
Asia, Southeast	51.22	4.8	2.48	5.30	11.13	114	349
EUROPE	**160.18**	**6.2**	**9.95**	**13.95**	**18.65**	**40**	**87**
Europe, Western	97.27	7.2	6.98	10.03	13.44	44	93
Europe, Central	23.61	4.7	1.10	1.57	2.10	43	91
Europe, East	39.30	4.8	1.87	2.36	3.10	26	66
THE AMERICAS	**120.74**	**6.5**	**7.82**	**14.78**	**27.08**	**89**	**246**
North America High Income	63.67	6.9	4.38	7.13	11.01	63	151
Caribbean	5.06	6.5	0.33	0.62	1.04	88	215
Latin America, Andean	4.51	5.6	0.25	0.59	1.29	136	416
Latin America, Central	19.54	6.1	1.19	2.79	6.37	134	435
Latin America, Southern	8.74	7.0	0.61	1.08	1.83	77	200
Latin America, Tropical	19.23	5.5	1.05	2.58	5.54	146	428
AFRICA	**71.07**	**2.6**	**1.86**	**3.92**	**8.74**	**111**	**370**
North Africa / Middle East	31.11	3.7	1.15	2.59	6.19	125	438
Sub-Saharan Africa, Central	3.93	1.8	0.07	0.12	0.24	71	243
Sub-Saharan Africa, East	16.03	2.3	0.36	0.69	1.38	92	283
Sub-Saharan Africa, Southern	4.66	2.1	0.10	0.17	0.20	70	100
Sub-Saharan Africa, West	15.33	1.2	0.18	0.35	0.72	94	300
WORLD	**758.54**	**4.7**	**35.56**	**65.69**	**115.38**	**85**	**225**

International, 2010). Yet, the prevalence estimates in developing countries is underestimated due to the lack of research in these areas. To fuel the fire even more, dementia ranks as the second most burdensome chronic disease and accounts for 11.9% of years lived with disability among all chronic non-communicable diseases (Alzheimer's Disease International, 2009). This latter point calls for a greater need in caregivers and the complexities of this will be discussed later in more detail.

Economically, dementia costs in 2010 totaled $604 billion worldwide. To put it into perspective, if dementia was a company it would have greater revenue than Wal-Mart ($414 billion) or Exxon Mobil ($331 billion). Overall, informal care (unpaid care) and direct costs of social care such as community care and residential homes each made up 42% of total costs followed by direct costs of medical care with 16%. Middle and high income countries totaled 99% of global costs. The biggest cost drivers in high income countries were institutionalized care (41%) followed by informal care (33%) (Alzheimer's Disease International, 2010). However in developing countries, there has been little work on evaluating direct and indirect costs because dementia is viewed as a low priority, there are poorly established health services which are therefore hard to quantify, and fewer health economists have explored these regions (Alzheimer's Disease International, 2009). Most likely due to the lack of institutionalized care and healthcare resources, informal care makes up 58% of costs in low-income countries versus 40% in high-income countries. This has important implications to women that will be later discussed (see table presented on page seven) as a majority of caregivers are women, specifically daughters and spouses (Alzheimer's Disease International, 2010).

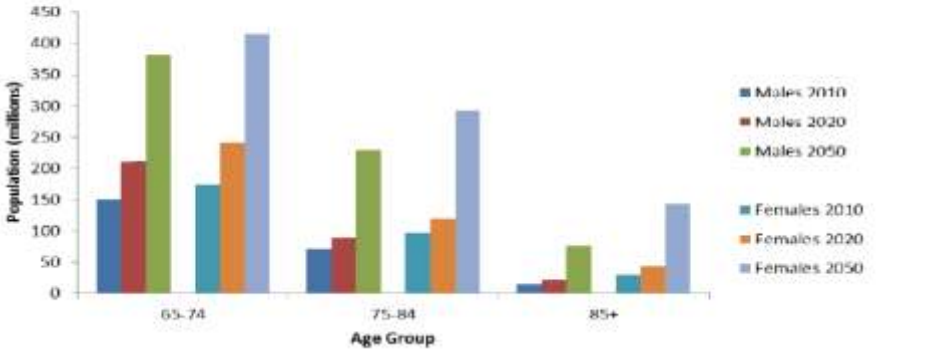
WOMEN AND DEMENTIA

Sex: What do we know about prevalence and incidence?

The greatest risk factor for dementia is age and as women are living to an advanced age and have a greater average life expectancy worldwide than men's, more women will get dementia. As previously mentioned, the risk of dementia doubles every five years after age 65 and one of the fastest growing age groups among women is known as the "oldest old" or those over age 85 which therefore has the highest risk (Bamford, 2011). According to the WHO, women make up 55% of adults over 60 and 58% over age 70. In low- to middle-income countries there are 270 million females over age 60 versus 115 million in high-income countries.

This eliminates the perception that ageing is only a concern among developed countries with high incomes, education, and access to healthcare services (World Health Organization, 2009). Elderly women are expected to surpass men in all age groups seen in the figure here and by 2050, women over the age of 60 is expected to reach one billion (World Health Organization, 2007).

Figure 1, World Midyear Population by Age and Sex for 2010, 2020 and 2050. (Obtained from the US Census Bureau Database)



This is a women's issue and the prevalence of dementia demonstrates this notion. In a majority of the age groups, women have higher prevalence rates than men regardless of a country's income. Especially in the oldest age group, there is a significant association between age, sex, and dementia except in urban India and rural China seen in the table below (Bamford, 2011). Because Alzheimer's disease is a very chronic and progressive disease, more women due to increased life expectancy and higher prevalence, live with additional co-morbidities and disabilities (Mathers & Leonardi, 2003). Incidence is believed to be a better measure of disease risk, but

Table 1, Prevalence of dementia per 100 persons by age and sex.

	65-69		70-74		75-79		80-84		85-89		90+	
	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female	Male	Female
Australia*	0.8	0.3	2	1.3	3.2	3.1	5.8	7.4	16.4	23.9	-	-
Canada*	-	-	4.5	4.6	8.2	9.1	15.1	17.4	22.6	28.1	30.4	41.1
England and Wales*	2.2	1.8	-	-	8	10.3	-	-	18	26	-	-
France*	-	-	-	-	7.7	5.7	12.5	16.6	22.9	29.9	27	52.8
Germany*	-	-	-	-	-	-	-	-	-	-	-	-
Japan*			-	-	-	-	-	-	-	-	-	-
Spain*	1	0.4	1.2	2.9	2	2.4	4.3	8.9	9.3	14.8	15.4	28.1
Sweden*	3.4	2.5	-	-	7.7	9.6	-	-	21.9	26.1	-	-
USA*	1.6	1.3	2.9	1.3	7.2	7.7	15.5	15.1	23.5	28.4	29.9	42.2
EuroDem**	1.6	1.0	2.9	3.1	5.6	6.0	11.0	12.6	12.8	20.2	22.1	30.8

	65-69		70-74		75-79		80+	
	Male	Female	Male	Female	Male	Female	Male	Female
Cuba***	2.9	2.9	5.9	6.1	6.6	9.8	23.2	26.6
Dominican Republic***	4.8	3.5	6.2	7.1	14.4	11.7	17.2	25.5
Peru Urban***	3.6	2.3	3	2.2	8.3	7.9	19.3	27.2
Peru Rural***	1.3	5	3.5	7.2	8.3	5.7	6.9	17
Venezuela***	3	2	2.3	3.5	6.5	5.1	17.2	20.7
Mexico Urban***	0	0.5	5.1	4.3	3.8	13.5	16.3	25.2
Mexico Rural***	0	2	2.9	6	6.9	9.7	20.7	22.9
China Urban***	0	2.9	3.7	3	6	8	14.7	24.4
China Rural***	1.6	1.6	3.1	4.2	9.1	9.6	19.6	14.7
India Urban***	2.9	5.5	5.5	7.4	4.5	8	25	21.2
India Rural***	4.3	7.8	5.8	14.8	5.7	15.7	11	29.4

Notes:*OECD numbers taken from Moise and Schwarzinger (2004), Eurodem numbers represent figures taken from Mathers & Leonardi (2000)
***Numbers for Latin American countries, India and China taken from Rodriguez et al (2008) and represent prevalence within 10/66 project sites

few studies have discovered a significant sex difference in dementia except those over the age of 85. Andersen et al. found an increased risk for Alzheimer's disease in women. A large sex difference was found for incidence rates after age 90 as women had a rate of 81.7 compared to men with a rate of 24.0 (Andersen et al, 1999). There are methodological concerns with incidence studies which include small sample sizes and varying diagnostic criteria. A better understanding of incidence is still needed in order for cross-country comparisons (Bamford, 2011).

Sex: Women and disability

A paradox exists because even though women are living longer, they are not necessarily living healthier. Disability in females will rise because of the ageing population and more women will be in the oldest age group (85+) where disability is most common. Researchers reported disability-adjusted life years (DALYs) for all dementias is twice as high among females compared males therefore causing a greater burden on women (Mathers & Leonardi, 2003). Not only are women affected by dementia more in terms of numbers, but they are suffering worse. A recent study found that prevalence and incidence of Alzheimer's disease is greater in women along with men outperforming women on multiple cognitive tests. When controlled for age, education and other skills, women suffer worse at the same stage of disease than men. Five cognitive areas were tested resulting in men having a small but significant advantage in all domains than women. Cognitive functions affect women both widely and severely which is hypothesized due to los estrogen in postmenopausal women, differences in Alzheimer's disease pathology between sexes, and a greater cognitive reserve in men acting as a protective risk factor. Although there is limited evidence that females with Alzheimer's deteriorate faster and suffer more than males, more studies are needed (Irvine, Laws, Gale, Kondel, 2012).

Sex: Underlying biological risks

The exact cause of Alzheimer's disease and other dementias is unknown but there are notable risk factors that result from a complex relationship between modifiable and non-modifiable risk factors that affect women in different ways than men. The Framingham Heart Study conveyed that women's lifetime risk of dementia is one in five while men's is one in ten (Seshardi & Wolf, 2007). Along with sex, some studies have found genetic factors with an association between certain genes and dementia in women. Hormones too, specifically reproductive hormones in women and declining estrogen levels in postmenopausal women

increase their risk. Cardiovascular risk factors, both modifiable and non-modifiable, can lead to dementia. For instance, cardiovascular disease and stroke contribute to vascular dementia which some argue, is more prevalent in men. Factors such as hypertension, smoking, poor diet and physical inactivity place both men and women at risk for these conditions. Though hypertension is found in more men up to age 60, a shift occurs thereafter and becomes more prevalent in women. In the Framingham Heart Study, 75% of the cohort over the age of 80 had hypertension and majority was females (Bamford, 2011). Sex and biological factors place women in a unique and emergent position warranting greater attention and focus among dementia priorities.

Gender: Women and the role of caregiving

Gender, a socially constructed term and its meaning varies country-by-country but a universal cross-cultural and cross-national gender role among women exists as a caregiver. There is a continued disparity between genders as more women than men shoulder the responsibility to care for loved ones disabled by the disease. Dementia being the chronic and progressive disease that it is creates a greater need for care which escalates over time. In both developed and developing countries, multiple studies have shown that women provide the cornerstone of care (Bamford, 2011). The 10/66 Dementia Research Group who studied Latin America, India, and China along with the EUROCARE study that examined 14 European countries all revealed more women act as caregivers, specifically daughters and daughters-in-law excluding rural China (Shaji, Smitha, Praveen Lal, Prince, 2002; Schneider, Murray, Banerjee, Mann, 1999).

In the United States, 60% of Alzheimer's caregivers are women and about one-third of them provide care 24 hours a day, seven days a week but 40% say they have no choice in the matter. Women report that the burden of caregiving puts a strain on their finances, health, and relationships. In developed countries, this has tremendous implications on the workforce and creates a heavy weight on women in numerous ways. Especially in the U.S. as Alzheimer's disease is expected to triple by 2050 due to ageing baby boomers, many women known as the sandwich generation, are responsible for rearing the future generation while taking care of the previous generation. About one-third of women caregivers reported acting as the primary caregiver to both their children and parents. Gender roles in high income countries are different than developing countries as more women are educated and financially independent. But the effect on the workforce due to caregiving responsibilities is substantial as much of the care provided is informal and unpaid. 56% of caregivers are employed (43% full-time and 12% part-

time) and because of the caregiver role women take on, they report significant repercussions. Of women providing care, two-thirds say they are frequently late to work, have to leave early, or take time off to provide care in addition to health problems they experience themselves. Due to the strain caregivers experience and their absenteeism, 20% believe they were penalized by employers as they felt less supportive for elder care versus child care which is a significant cultural value that varies among countries. About half of all women caregivers report high rates of physical and emotional stress. All of these important points have major cost implications such as lost wages due to absenteeism and costs of negative health outcomes among caregivers. In the United States, annual costs are estimated at $56,800 per patient with Alzheimer's disease while 60% of that is borne by families (Shriver & Alzheimer's Association, 2010).

There are still challenges though in developing countries as women are largely responsible for caring for loved ones with dementia. In the 10/66 Dementia Research Group's study, the chart here displays that the majority of caregivers are women excluding rural China. Most of the female caregivers are wives, daughters, or daughters-in-law (Alzheimer's Disease International, 2009). But even though in some areas women have made great strides in equality issues, women still need specific attention as they are particularly vulnerable to inequalities in low- and middle-income countries where poverty, low education, and little access to healthcare services continues to be dominant. Because formal care is virtually nonexistent in these countries (and even if it was, families would unlikely able to bear its finances) so informal and unpaid care is relied upon (Bamford, 2011). Among low- and middle-income countries, 7.4 hours a day was the average amount of time spent caring for a loved one

Table 2.3
Household living arrangements, and characteristics of the main carer for people with dementia in 11 sites in Latin America, China and India. (10/66 Dementia Research Group population-based studies – data release 2.2)

10/66 DRG study site	n	Household living arrangements				Characteristics of the main carer			
		Alone	Spouse only	Adult children	One or more children under the age of 16	Spouse	Child or child-in-law	Non-relative	Female carer
Cuba	316	6.3%	10.2%	54.7%	33.7%	17.3%	67.7%	5.8%	80.0%
Dominican Republic	235	8.5%	10.2%	48.5%	39.9%	21.4%	44.6%	11.6%	81.3%
Venezuela	140	5.7%	4.9%	68.1%	53.8%	13.7%	68.4%	2.8%	80.7%
Peru (urban)	129	1.6%	9.4%	54.3%	27.1%	13.0%	41.6%	30.1%	83.7%
Peru (rural)	36	13.9%	8.3%	63.9%	38.9%	16.7%	58.4%	2.8%	86.1%
Mexico (urban)	86	14.0%	9.3%	55.8%	38.4%	5.8%	79.1%	3.5%	83.7%
Mexico (rural)	85	16.5%	11.1%	55.3%	31.8%	12.9%	68.2%	2.4%	76.5%
China (urban)	81	2.5%	34.5%	38.3%	7.4%	36.1%	47.3%	13.9%	66.7%
China (rural)	56	3.6%	8.9%	75.0%	60.7%	42.9%	57.1%	0%	35.7%
India (urban)	75	4.0%	13.3%	72.0%	49.2%	26.7%	40.0%	0%	69.3%
India (rural)	106	15.1%	5.7%	67.0%	52.8%	23.3%	70.0%	0%	80.2%

with dementia. This includes supervision, personal activities of daily live (washing, eating, dressing, etc.), and instrumental activities of daily life (managing finances, cooking, shopping, etc.) (Alzheimer's Disease International, 2009).

Gender: Societal Norms

It was recently exposed that the rate of those living alone is on the rise across the world. It is predicted that there will be a worldwide jump in adults living alone, up 20% by 2020. "Singledom" as it is referred to have become a phenomenon in the U.S. as 50% of adults are unmarried which is a dramatic growth from 22% in 1950. This translates to 15% of American adults living alone, an increase from 4%. Even in the Gulf, more women are putting off marriage. The United Arab Emirates' Marriage Fund reported that 60% of women over 30 are single, a tremendous increase from 20% in 1995. Because of a change in societal trends as women are putting off marriage for career aspirations for instance, there are more single adults meaning fewer children. A trend like this could have a profound effect on supporting and providing care to the ageing population and those with dementia. The factors that are driving this movement across the world are different, however. Cultural values are beginning to shift as industrialization is sweeping through many countries triggering a change in values and norms as more women are becoming educated, financially independent, and delay marriage (Baker, 2012). Therefore, informal caregiving by women is being threatened in developing countries due to social and economic changes. First, women are becoming more educated which means more are participating in the workforce reducing their availability to provide care. On top of that, as more populations are becoming educated, they are more mobile and can travel with fewer expenses as flexible labor markets are evolving. Many children then migrate to different cities or countries in seek of employment and leave their parents behind. In countries like China, there are laws against fertility such as the one child family law which perpetuates the demographic gap as the ageing population increases creating a greater need for the younger generation to provide care (Alzheimer's Disease International, 2009).

The structure of societies and their gender norms place women in a disadvantaged position within the population regardless of a country's economic status but in low- and middle-income countries, the proportion is more pronounced. Education is more infrequent among girls than boys and when families with limited resources choose to send their children to school, more times than not they elect to send their boys as they are expected to take on the breadwinner role.

Two-thirds of adults who cannot read or write are women and the gap is expected to grow. All of these structures and norms act as a barrier to healthcare. Feminization of poverty is also challenging and creates a global health issue for women as laws exists surrounding property ownership and inheritance laws creating a barrier to financial independence. Of the 1.3 billion people who are poor in the world, 70% are women of all ages. In some countries where women are discriminated against because of age, sex, and disease status is known as "triple jeopardy." Because dementia has a stigmatizing nature, it acts as a disincentive when seeking care especially in some places of the world where the disease is seen as "madness" and continues to advance social isolation. Just like in developed countries, community outreach is needed to educate and help mobilize resources. But overall as dementia prevalence rapidly increases in these parts of the world, women are going to bear the burden directly as the patient as well as acting as a caregiver (Bamford, 2011).

WHAT NEXT?

A major stride for the Alzheimer's disease and dementia movement occurred when the WHO announced dementia as a public health priority (World Health Organization, 2012). Calling global attention to this issue is an important accomplishment to fuel research, advocacy, and outreach so policymakers and critical stakeholders can mobilize resources. However, dementia needs to be declared a woman's global health priority so the crucial step can be taken to prioritize this chronic disease. This fits into the first three of the eight Millennium Development Goals orchestrated by the United Nations: Goal one "to eradicate extreme poverty and hunger," goal two "to achieve universal primary education," and finally goal three "to promote gender equality and empower women" (United Nations, 2012). Each of these overarching goals can be tied into women's health and dementia. More focus is needed however on chronic disease as this is an emerging issue in developing countries while much of the UN's attention is still on infectious diseases. So in order to lessen the heavy burden that women will inevitably carry, declaring dementia as global women's health issue is desperately needed to prevent the individual, social, and economic consequences that will undoubtedly occur in coming decades.

In addition to calling global attention on dementia as a woman's health issue, other measures can be taken. To start, additional research on incidence, prevalence, and disease burden is needed especially in developing countries (Bamford, 2011). The chart here depicts annual expenditures for Alzheimer's associations and the little funding put into research by country. These figures are daunting especially for Japan as this country along with Asia in general has prevalence rates that are dramatically increasing (Alzheimer's Disease International, 2009). But in order to continue drawing attention to this disease, Alzheimer's and dementia associations need to be established especially in low- and middle-income countries. All of these recommendations call for more funding. But in general, sex and gender needs to be considered and incorporated into public health policies and programs. Another emphasis is needed on increasing awareness in order to educate populations and decrease stigmatization that is attached with the disease especially in areas where social isolation is a widespread consequence of mental health issues. Prevention efforts also need to be improved, especially with modifiable risk factors such as smoking, poor nutrition, and physical inactivity (Bamford, 2011).

Association	Budget	Budget in US$
Australia	AU$400,000	329,500
Canada	CAD 2,192,000	1,980,000
France	€ 1,010,862	1,424,834
Germany	€ 105,000	148,000
Ireland	€ 50,000	70,476
Japan	JPY 3,600,000	360,000
Netherlands	€ 849,000	1,197,000
Scotland	GB£ 100,000	165,000
Switzerland	CHF 379,000	351,000
Sweden	SEK 10,000,000	1,412,000
UK	GB£ 2,093,000	3,445,000
USA	$ 32,335,000	32,335,000
Total		**43,217,810**

Data collected from ADI member associations. Figures are for most recent year available (2007/2008)

CONCLUSION

The sex and gender implications of being a female prove strong evidence to declare dementia as a global woman's health issue and priority. As the average life expectancy for women increases, especially among the "oldest old" group, more women are at risk of dementia (Alzheimer's Disease International, 2010) but a paradox exists because although women are living longer, they are living with more disabilities stemming from dementia (World Health Organization, 2009). Not only are the numbers not in women's favor, but some research

indicates women decline at faster speeds than men regarding cognitive functions (Irvine, Laws, Gale, Kondel, 2012). Because the total dementia prevalence is expected to triple by 2050, women will be affected in other ways (Alzheimer's Disease International, 2010) as they become primary caregivers for loved ones in most countries meaning decreased participation in the workforce and a loss in wages (Bamford, 2011). In fact, a majority of total costs from dementia derive from informal, usually unpaid care provided by spouses, daughters, and daughter-in-laws (Alzheimer's Disease International, 2010). Women are in jeopardy particularly because of gender disparities as more women are less educated, face higher poverty rates, and are valued less in certain societies. This is of concern especially in developing countries which intensify the disparities and inequalities women currently face and will continue to experience unless persistent action is taken at a national and global level by declaring dementia as a woman's health issue (Bamford, 2011).

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